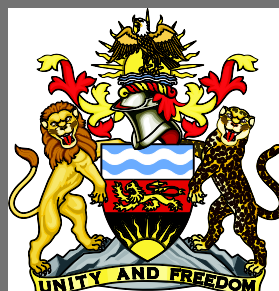# SITUATION ANALYSIS:

# REFERRAL MECHANISMS AND THE WORK OF EXPERT CLIENTS IN MALAWI

JULY 2011

CATHOLIC RELIEF SERVICES

# CONTENTS

**ACRONYMS**

| | |
|---|---|
| AIDS | Acquired Immune Deficiency Syndrome |
| ANC | Antenatal clinic |
| ART | Antiretroviral therapy |
| CBO | Community based organization |
| CHAI | Clinton Health Access Initiative |
| CHAM | Christian Health Association of Malawi |
| CHW | Community health worker |
| CRA | Community referral agent |
| CRS | Catholic Relief Services |
| CPT | Cotrimoxazale prophyaxis therapy |
| DHO | District Health Officer |
| DHMT | District Health Management Team |
| EHP | Essential Health Package |
| HBC | Home based care |
| HIV | Human Immunodeficiency Virus |
| HTC | HIV Testing and Counseling |
| HSA | Health Surveillance Assistant |
| IMPACT | Integrated HIV-effect Mitigation and Positive Action for Community Transformation |
| KCH | Kamuzu Central Hospital |
| LTFU | Loss to follow-up |
| MSH | Management Sciences for Health |
| MSF Belgium | Médecins Sans Frontières Belgium |
| MIP | Mother-infant pair |
| MoH | Ministry of Health |
| M2M | Mothers to Mothers |
| NAC | National AIDS Commission |
| NAPHAM | National Association for People Living with HIV and AIDS |
| PLHIV | People Living with HIV |
| PMTCT | Prevention of mother to child transmission |
| PIH | Partners in Hope |
| TB | Tuberculosis |
| TWG | Technical Working Group |
| OPD | Outpatient Department |
| OVC | Orphans and Vulnerable children |

**EXECUTIVE SUMMARY**

In January 2011, the joint Ministry of Health (MoH) ART/PMTCT Technical Working Group established a Task Force to facilitate the development a common referral mechanism to support early diagnosis and treatment for people living with HIV as well as their retention on longitudinal care. The Task Force was also given the responsibility to review existing and upcoming initiatives that apply the Expert Client methodology and recommend promising practices that could be scaled up by new HIV programs to expand access and retention in care.

The USAID- and PEPFAR-funded IMPACT Program will be working in collaboration with the MoH and other key stakeholders to support the national referral mechanism and procedures for engaging Expert Clients. One of the objectives of IMPACT program is to improve access to treatment for people living with HIV (PLHIV) in nine districts of central and southern regions. To achieve this objective, IMPACT works through community and MoH structures and in collaboration with existing HIV initiatives. At community and facility level, IMPACT will work with PLHIV support groups. The program will train and engage Expert Clients in promoting HIV Testing and Counseling (HTC), referring clients to health services for assessment and treatment, and following them up to ensure adherence to treatment.

A situation analysis was commissioned by the Task Force to document the various referral models and mechanisms that institutions are currently using and the manner in which volunteers are engaged in health and HIV activities. Catholic Relief Services (CRS) IMPACT Program was asked to lead the study on behalf of the Task Force.

Twelve organizations, including MoH, participated in this exercise, conducted in March and April 2011. The study found that every institution had a referral model, which varied in nature and scope. Primarily, there are two types of models that are used by these organizations: one-way (open loop) or two-way (closed loop). Most organizations use the already established MoH referral model, either as it is or with modifications. Respondent organizations indicated that the two-way model presents more benefits to users and beneficiaries than the one-way referral model. Benefits include increasing access to care and treatment, reducing defaulter rate and loss-to-follow-up (LTFU) and maintaining high level of adherence to treatment. Poor documentation of referrals, lack of interest among staff to follow up referrals and limited resources to print referral forms featured prominently as significant challenges affecting functionality of the referral mechanisms and continuity of service delivery.

The study also found that the organizations deployed different kinds of volunteers involved in HIV care and treatment at community and health facility levels with varying nomenclature. Titles include Expert Client, community health worker (CHW), mentor mother, community activist, community referral agent (CRA) and community home based volunteer (CHBV). Mentor

mothers and activists are, in effect, Expert Clients because they are disclosed HIV positive peers while CHWs, CRAs and CHBVs, whose HIV status is unknown, are not Expert Clients. As peers to those they serve, Expert Clients provide the much-needed link to care, treatment and support for PLHIV, bridging between community and health facility.

Each organization surveyed use a set of criteria to select Expert Clients, which vary widely from one organization to another. All organizations provide training and supervisory support to maintain commitment and motivation. Most Expert Clients receive a stipend to cover transport costs and lunch costs. However, M2M and MSF Belgium pay Expert Clients as regular employees, thus are not considered "volunteers". As a result of engaging the Expert Clients, most organizations report increased referral for HTC, PMTCT and ART services and reduced loss-to-follow-up (LTFU), indicating that the volunteers are filling an important gap in service delivery. Unfortunately, most organizations do not have a clear sustainability or transitioning plan for the Expert Clients, which implies that their work is likely to be discontinued when the funding stops.

There is no doubt that agreeing upon a common, functional national referral mechanism would increase access to care and treatment for people living with HIV. Tackling the challenges experienced with existing referral mechanisms will ensure that clients are diagnosed early and remain in the continuum of care, thus improving health outcomes for clients. Expert Clients are a valuable cadre that can strengthen the health care system. Their involvement in HIV care and treatment serves an important connecting role that should be promoted. For continuity of services to PLHIV, clear transitioning plans need to be established by each implementing organization or program.

## BACKGROUND

CRS Malawi's USAID-funded IMPACT program aims to improve care and support for orphans and vulnerable children and access to treatment for people living with HIV (PLHIV) in nine districts of central and southern Malawi. Currently, several organizations engage community volunteers to bridge the gap in services between the community and health facilities. During a MoH HIV Technical Working Group (TWG) meeting (February 23, 2011), CRS proposed that it undertake two activities on behalf of the TWG. First, IMPACT proposed a review of referral mechanisms designed to reduce LTFU in the continuum of care. This responds to a broad acknowledgement that although the healthcare system has inbuilt referral mechanisms, there seems to be no comprehensive functional system. Numerous challenges to functionality have been noted, including staff shortages, limited resources, lack of documentation and lack of feedback to the source.

The second activity relates to the use of Expert Clients. At present many partners in Malawi are using Expert Clients for a range of tasks, at both health facility and community levels, with significant success. It was deemed valuable to reach consensus on the key roles and responsibilities of Expert Clients, consolidate training materials and reach consensus if possible on issues of remuneration and sustainability. Members of the TWG mandated a task force to facilitate the process and asked CRS/IMPACT to take the lead.

It was agreed that the Task Force's work would primarily focus on reviewing the findings of the situation analysis since different programs are using different models. This exercise was therefore conducted in response to this call with the aim of understanding the models, in terms of what is working well, challenges and lessons learned, financial and human resource implications to aid decision making in strengthening the referral mechanisms in Malawi, and to understand the work of volunteers, especially the Expert Clients.

## INTRODUCTION

### The Health Care System

The MoH provides essential health services (EHP) at different levels of the health care system, which are linked through a referral chain consisting of a hierarchy of health facilities or levels of care from the primary level upwards. Treatment protocols guide staff as to the type of interventions they can handle at each level and when to refer cases. The health care delivery model in Malawi is organized in three levels: primary (health posts and health centers) secondary (district and rural hospitals) and tertiary (central hospitals). Referral of patients follows these levels from primary level up.

**Health post at community level**

Each community is supposed to have a health post or village clinic managed by Health Surveillance Assistants (HSA). Although not all communities have a village health post, HSAs are still functional at community level. They are the main providers of services at this level of the health care system. The HSAs are complemented by other community health providers such as volunteers from NGOs, traditional birth attendants and others. Health Center staff and Village Health Committees oversee the delivery of community based health services. At the community level the recommended staffing levels consist of 1 HSA per 1000 population. Initial training for HSAs is six months in duration.

HSAs are trained in several areas including integrated community management of childhood illnesses (IMCI). They provide the first line curative and preventive care and refer cases beyond their jurisdiction such as acute respiratory infections, severe malaria cases, pregnant women and babies born at home for ANC. Although more HSAs have been trained and deployed in recent years, the numbers are still insufficient for each community given the myriad tasks an HSA must focus on. In addition, finding housing for HSAs within communities is a challenge, forcing most HSAs to reside outside of the communities they are assigned to serve. HSAs are also provided with medications and health supplies, but quantities are generally not adequate and stock outs do occur. This situation contributes to congestion experienced in health facilities.

**The health center level**

The health center (dispensary and maternity unit) is the most basic health unit with the capacity to deliver the full essential health package (EHP). The recommended staffing levels for the health center to deliver the EHP effectively consists of 2 Enrolled Nurse/midwives, 2 Medical Assistants and 10 Health Assistants. The District Health Management Team (DHMT) provides support and supervision to the health center.

Staff at the health center (nurses, medical assistants and clinical officers) are responsible for treating clients referred by the HSAs and provide referral support to district hospitals. The health facilities are supported by a team of specialists from within the district, but this doesn't always happen due to availability issues. Health center staffs work with the area health committee to develop local health plans and budgets that will contribute to overall district plans.

Health centers often use the Outpatient Department (OPD) to filter patients to Antenatal, family planning and other units. The health center has a motorbike or ambulance for transporting referred clients to the district hospital. EHP services that are delivered at the health center level include those services offered at the community level and those that cannot be managed by the HSAs.

The health center is responsible to ensure the constant flow of medical supplies to the community level, coordinating and conducting training for community based providers. Due to

lack of human resources at community level, some health centers run health post activities. Sometimes the infrastructures are poor, drugs are not available and staff is in adequate limiting access to care.

**Community hospital**

The health care system has provision for a community hospital to manage referrals from the health facilities. Unfortunately, there are only two community hospitals in Malawi based in Lilongwe (Kabudula and Mitundu). The community hospital only manages some conditions but for major conditions, they refer to a district hospital. In the absence of community hospitals, clients from health facilities are referred to a district hospital.

**District hospital**

This level provides referral support for EHP cases from health centers, maternity units and dispensaries and Christian Health Association of Malawi (CHAM) institutions. They serve a catchment area of over 250,000 people. They also provide technical supervision and support. Health services are managed by the DHMT headed by the District Health Officer (DHO). The DHMTs receive direct technical support from the five Zonal Health Support Offices. The district hospital provides the clinical interventions of the EHP and ensures that all EHP services are delivered and available on a daily basis and patients who require referral to central hospitals do so expeditiously. The EHP services delivered at the District and CHAM institutions are over and above those delivered at the health center level.

**Central hospital**

Central hospitals provide the highest level of medical care in Malawi, handling the EHP cases referred from both the public and private sectors. Malawi has five central hospitals: Mzuzu Central Hospital, Lilongwe Central Hospital, Queens Central Hospital, Zomba Central Hospital and Zomba Mental Hospital.

There are some districts without a district hospital such as Zomba, Phalombe, Likoma, Mzimba North and Blantyre. Clients from these areas therefore are referred from health centers straight to their nearest central hospitals. The central hospitals are the last referral point in the country for all patients in need of specialized care. If central hospital cannot manage any referred cases then arrangements may be made to refer to private hospitals such as Mwaiwathu, Adventist, and Beit Cure, but treatment must be provided free of charge to the client. The referring district pays for the client referred. All patients in need of referral beyond this point are referred abroad using guidelines.

The most significant challenges for hospitals include shortage of human resources, poor documentation, in adequate supply and or shortage of drugs. The staff shortage contributes to a weak referral system. There are more clients lost to follow- up. In rare circumstances hospital staff may walk with the clients from one service delivery point to another. Directions to service points are often in English without translation or accompanying symbols, making access difficult

for Chichewa speaking or illiterate clients. As a result, many are lost even before they leave the health facility. People may be given appointments to visit the facility/hospital on specific dates, but there are few consistent systems for documentation or reminders for follow- up to such patients should they fail to report for scheduled appointments. Record keeping related to referrals is poor; not all facilities or district hospitals keep records of number of people referred making it difficult to assess whether the referred clients indeed received the services. Back referral forms are available in some areas but these are not being tracked. In the past some hospitals and facilities tried back referral, but found it difficult to implement reliably. There is no focal person designated to handle referrals

**PURPOSE OF THE SITUATION ANALYSIS**

The situation analysis was commissioned by the HIV Technical Working Group primarily to support the establishment of a functional national referral mechanism. While there are various referral models in use by organizations and programs in the country, these tend to be limited in time and scope as they are developed for purposes of supporting individual projects. Furthermore, the MoH national health care referral system falls short of meeting the needs of most programs and communities that need care. There is no consensus among HIV and AIDS stakeholders on what constitutes a model referral system. The commissioning of the situation analysis opens a door for dialogue among stakeholders on what kind of system and how it should be established. Specifically, the situation analysis aimed to:

1. Determine the nature of existing referral systems or models currently being used by organizations in treatment and care programs.
2. Assess the strengths and limitations of existing referral models with the view to recommending effective models for adaptation at national level and by programs to improve access to treatment and care services and outcomes.
3. Documents the experiences of organizations and programs working with community volunteers, specifically Expert Clients, with the view to recommending promising approaches that have worked to improve coverage and quality of treatment and care for PLHIV.

**METHODOLOGY**

The situation analysis was conducted in several organizations in Malawi between March and April 2011 using qualitative methods, such as in- depth interviews and observations. Information was collected using a semi- structured questionnaire, which was administered to interviewees. Refer to Appendices 1 and 2 for the tools used. Respondents were mainly persons leading the implementation of HIV and AIDS projects and who were therefore familiar with the plans, processes and activities. One or two individuals in each organization were interviewed either individually or together by a team of two interviewers from CRS/IMPACT. In some cases the study team was referred to another person within the organization for further details or clarifications.

The interviews were conducted in English. Data was analyzed manually using emerging themes from the content of the discussions. Permission to conduct the exercise was sought from the Country Representatives/Directors of the organizations visited and verbal informed consent was obtained from all participants before the interviews commenced.

**RESULTS AND DISCUSSION**

A total of twelve organizations were visited during the exercise, including: MoH, Dream, Baylor, Lighthouse, Dignitas, MSH, M2M, BRIDGE II, Partners in Hope (PIH), Clinton Health Access Initiative (CHAI), MSF Belgium and PSI/PACT Malawi. Refer to Appendix 3 for characteristics of the institutions. The findings below are organized according to the seven themes that emerged from the study.

**Referral models**

The study found that most institutions have a referral model except for M2M which uses MoH mechanisms. Overall, the referral models aim at achieving the following:

- Strengthen referrals and linkages between communities and facilities/hospitals
- Promote and increase access to services
- Reducing gaps between the service providers and clients in need of services
- Improve drug adherence
- Focus attention on patient at high risk for poor outcomes
- Encourage appropriate health seeking behaviors
- Reduce LTFU.

The scope and entry points for the referral models vary among organizations. Table 1 below summarizes the scope and entry points of the referral models.

Table 1: Scope of the referral models and entry point

| Institution | Scope | Entry point |
|---|---|---|
| Dream Center | HIV | PMTCT |
| Baylor | HIV | PMTCT |
| Lighthouse | HIV & TB | HTC |
| MSH | HIV | OPD (HTC) |
| Dignitas | HIV | Paediatric ward, PMTCT, HTC & ART |
| BRIDGE ll | All health | OPD |
| PIH | HIV and OIs | HTC |
| CHAI | HIV | Under- 5 clinic, Maternity, NRU, ANC, ART & TB |
| MSF Belgium | HIV | PMTCT & ART |
| PSI/PACT | All health | HTC at facility; CBOs/NGOs in HIV at community level |
| M2M | HIV | PMTCT |
| MoH | All health | OPD |

The study found that there are two types of models that are existent; one way and two- way or closed- loop referral models. Most organizations use the already established MoH referral models, either with or without modifications. At Baylor, PIH in Lilongwe and Dream Center in Blantyre for example, clients are referred from the health facilities or communities to their institutions for management. Clients are referred further to Kamuzu Central Hospital and Queen Elizabeth Central Hospital respectively depending on circumstances. From the referral source, a health passbook or report is used. MSH, M2M and MSF Belgium use MoH's model in which patients are referred from health facilities to district hospitals by clinicians. Largely, it is a one-way referral model. Dream Center also uses a one-way referral model called dream model. The model involves activists (community volunteers) serving as a link between the community and the health center. This approach was adapted from a similar project in Mozambique.

Other organizations such as BRIDGE ll, Dignitas and PSI/PACT Malawi are using a two-way referral model that also emphasizes the linkage between communities and health facilities. The referral model uses community structures and health facility staff as well as community referral agents. Refer to Figures 1 and 2 for referral models for BRIDGE ll and PSI/PACT Malawi, respectively. MSF Belgium in Thyolo developed a two-way referral model but the system collapsed when they handed over the responsibility of distributing the forms to health facilities. It appears that communities and health facility staff did not understand the importance of the system and hence were not committed to support it.

Figure 1: A two-way referral model piloted by BRIDGE ll project
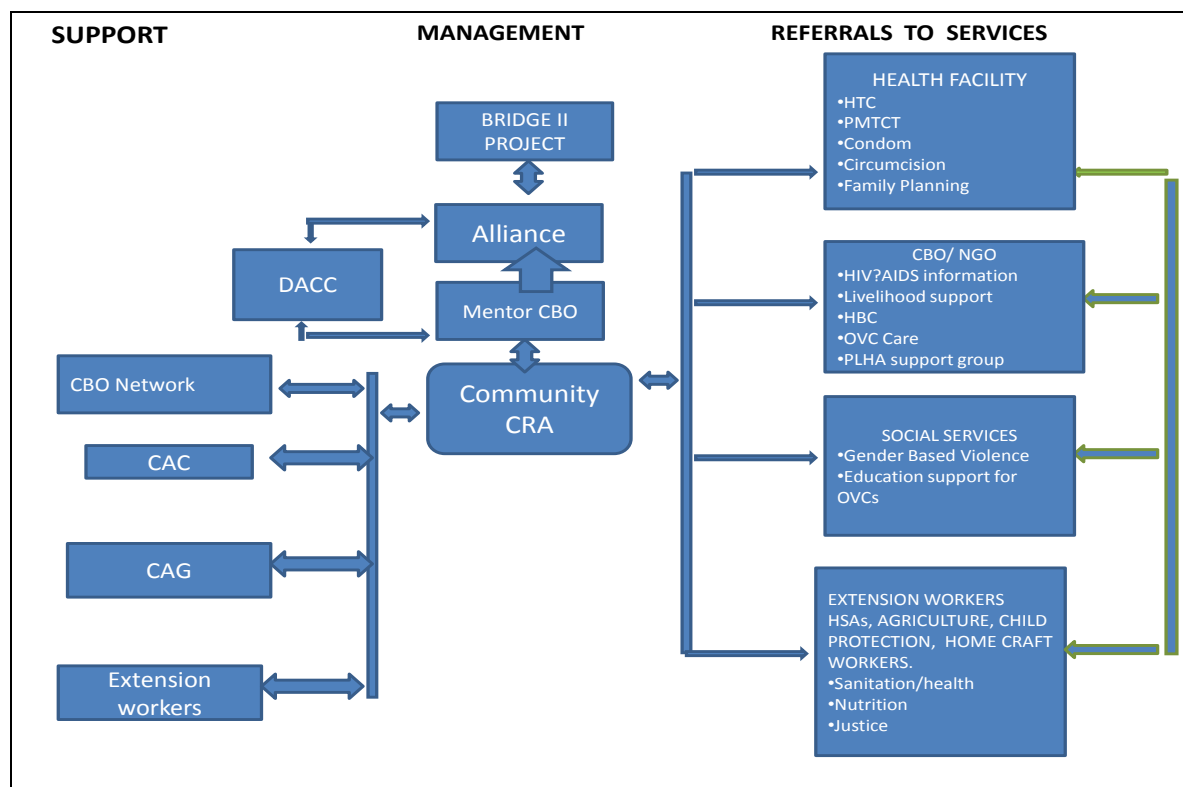
Some of the models, for instance those used by BRIDGE ll, Dignitas and PSI/PACT Malawi, were developed through a consultative process involving other key stakeholders within and outside Malawi and in collaboration with the DHMTs.

**Referral mechanisms**

The study found that institutions use various terms to describe their referral mechanisms. The names of the referrals include the Dream cycle model, community- to- facility referral, facility- to- facility referral, facility- to- community referral, Counseling and Testing site to services referral, ART & Home based care referral, transfer out referral, service- to- service referral, within- facility referral, outreach referral, people and paper- based referral, community based referral, health facility referral, and external referral. Some organizations adapted their referral models from other organizations involved in similar work. For example, PIH adopted their referral mechanism from Lighthouse.

Most of the referrals were designed to have a functional back referral mechanism but only Dignitas, PSI/PACT Malawi, MSF Belgium and BRIDGE ll have this mechanism in place. Lighthouse has this in place but it is not functional because of frequent staff changes at Kamuzu Central Hospital (KCH). Dignitas uses community- to-facility referral, facility- to-facility, and facility- to-community referral mechanism.

Figure 2: Referral model for PSI/PACT Malawi for HTC and other health services
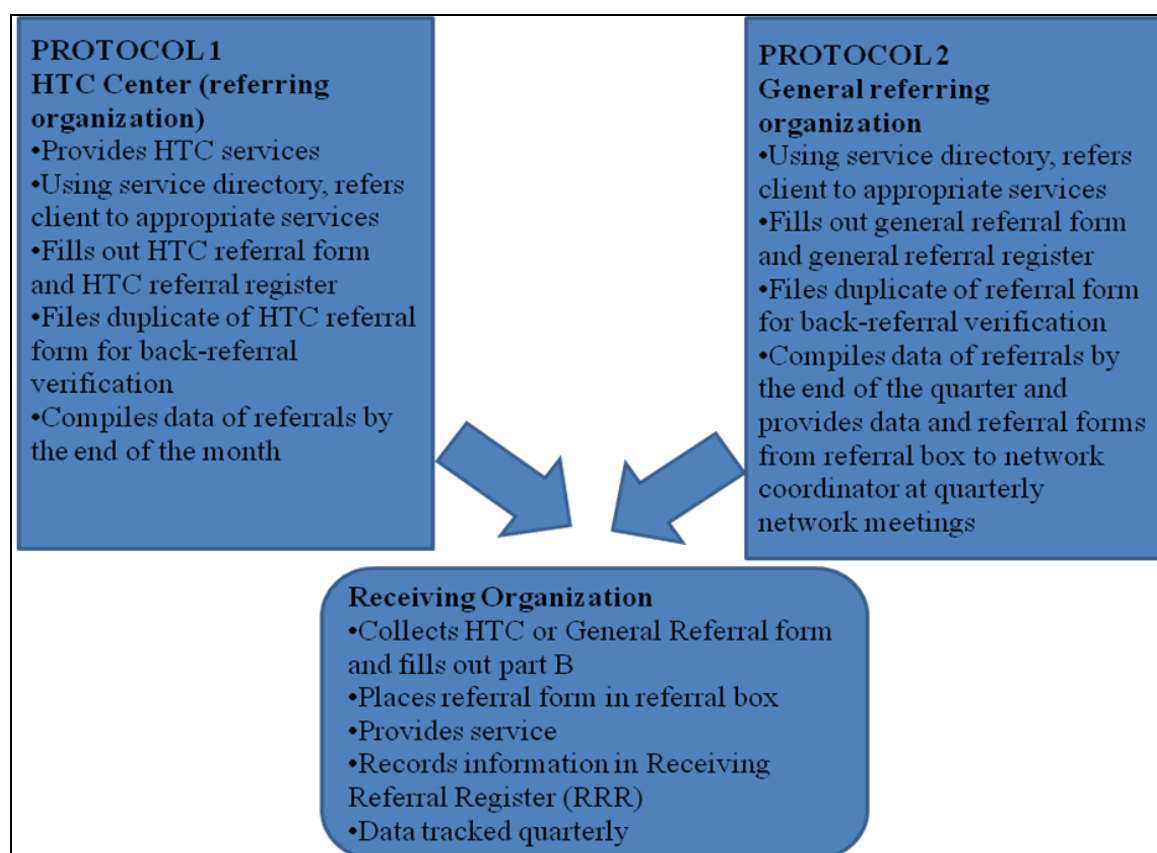
PSI/PACT Malawi has two referral mechanisms (community based referral and health facility referral) while BRIDGE ll uses People and paper- based referral mechanism. When people are referred from the community to facility or facility to facility, which include the district/central hospital, there is a designated person who follows up all the referred cases. The source has a referral register and/or referral copy which is given to the client. All receiving health service points have a box where the referrals are posted after the client is seen. The designated person from the referring institution collects the forms showing where clients were referred to on a monthly basis. The following are the strengths of these mechanisms as reported by the persons interviewed:

- Referral from the community level to health facilities/hospital has improved health outcome for several clients, such as a reduction in optimistic infections. Those clients referred for services who fail to access them are followed up to ensure that they obtain care. This increases the likelihood that a client benefits from clinical care services.
- The referral form has a section for feedback on how the client illness was managed. MoH representative said, "*This feedback is important for the clinician who referred the client to know how the patient was managed.*"
- The proportion of women supplied with nevirapine increased, the proportion of women put on CPT increased and defaulter tracing of mothers on ART increased. Dignitas for example, conducted a study to compare trend before and after implementation. Among women eligible for treatment with single dose nevirapine (185 pre- and 124 post-), the proportion of women supplied with nevirapine increased in the post-intervention group from 62.7 %[( 95%CI (55.7, 69.7)] to 91.9% [95%CI (87.1, 92.8)]. Among women eligible for CPT (196 pre- and 139 post-), the proportion of women put on CPT increased from 62.2% [95%CI (55.4, 86.3)] to 86.3% [95%CI (80.6, 87.1)]. Defaulter tracing of mothers on ART also increased post- intervention from 24.2% [95%CI (9.6, 38.9), n=33] to 88.2% [95%CI (72.9, 89.0), n=17].
- Improved access to care for men and couples. For example in BRIDGE ll, out of the 18,774 referrals, 41% of clients referred for HTC are men, 7% of clients referred for HTC are couples.
- Referral system has contributed to establishment of new support groups.
- More clients adhere to ART. For instance, MSF Belgium the cumulative defaulter rate for 2009 is 14% for the ART in Health Centers and the community.
- Reduced loss to follow- up because clients when managed at the facility are referred back to community structures and are managed right away in their community.

Despite the above strengths, the back referral model presents some challenges. For example, several programs cited poor documentation; that is documentation of referrals at the facility is not complete or up to date. As such the numbers of referrals do not often correspond with actual referrals seen at the hospital. In addition, some clinicians do not complete the referral form or do so only partially. A community Program Manager at Dignitas said, "*Sometimes the*

*feedback part is not filled even when they have assisted the client."* In addition, due to limited resources, referral forms supply may be erratic.

In addition, some health care providers clearly do not consider referral forms to be a part a core work function and request additional financial incentives to complete them. A project Manager for BRIDGE ll said, "*Use of referral forms is treated as an extra work. In some cases, a number of referred clients are sent back by service providers without proper explanation.*" This may be overcome by providing a stipend, but this approach has limited sustainability when fully transitioned to Ministry of Health. There may also be poor coordination between health service providers and referring agents at community level.

The MoH has a provision of back referrals in the referrals but the system is not working largely due to negligence of staff to fill in the form and provide feedback. The MoH representative said, "*Back referral forms are available but are not used in most cases. They are missed in the process and there is no focal person for referrals.*"

None of the organizations provided cost estimates for the referral mechanisms in use, but all provided volunteer maintenance costs. It was difficult for most organizations to estimate the cost of training, supervision, monitoring, printing of referral forms and transportation. However, based on the information given provided, one may deduce that the cost implications are significant. Table 2 below describes the types of referral mechanisms in detail.

Table 2: Referral mechanisms and functionality

| Institution | Type of referral mechanism | How it works | Strength & Impact | Weakness & challenges | Lessons learnt |
|---|---|---|---|---|---|
| Dream | Dream cycle referral | The referral is through clinicians from the center to Queen Elizabeth Central Hospital. Activists act as a bridge between Dream Center and the community. They refer clients from the community for care at Dream using a brief report concerning the illness of the client while clinicians assess the client and may treat at Dream or refer to Queen Elizabeth Central Hospital. The referral also includes follow up mechanism using professional nurses who follows up the critically ill individuals in their homes. Treatment may be continued at home or patient may be referred for further evaluation depending on situation. The system includes defaulter tracing mechanism. | - Referral is embedded within health management software. Referrals and defaulters are tracked electronically.<br><br>- As much as possible, clients are escorted to places where they are referred to especially to Queen Elizabeth Central Hospital.<br><br>- Due to defaulter tracing LTFU is reduced. | - One-way referral mechanism, therefore difficult to know the progress or treatment outcome of those referred.<br><br>- Very ill patients at times are not assisted when referred to some health facilities. | The follow up mechanism and use of activists have created a lot of demand for the services. |
| Baylor | -Facility-to-facility<br><br>-Facility-to-community | Baylor is working with health facilities in Lilongwe to build capacity for early identification of clients and initiation of treatment. Clinicians may refer clients from the health facility to Baylor and at times from Baylor to KCH. Depending on the needs of the client, one may be referred for HTC from the facility to the community through Tingathe program. Follow-up is done to children and pregnant/lactating women whether admitted or discharged by Baylor | - Ensures that the patient gets quality care<br><br>- Clients prefer to access services from Baylor than from other MoH health facilities.<br><br>- Increased number of HTC, increased patient enrollment from 50 in 2007 to 1,854 in 2010 for 3 MoH sites, increased mothers enrolled in PMTCT program. | - They have $1^{st}$ line and $2^{nd}$ line treatment. This is challenging for the referral system in cases of adverse drug reaction to $2^{nd}$ line treatment.<br><br>- Demand for the service is high since more people patronize services at Baylor than health facilities but resources are limited. Nurses are few and are burdened | - Earlier identification and referral to care has improved outcome- decreased mortality.<br><br>- Adherence supervision and defaulter tracking has compelled clients to remain in the continuum of care. |

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| | | nurses and doctors. | | - Although patients are followed up, some due to the transient nature of people living in the city. | |
| Lighthouse | - CT site to services referral<br><br>- ART & Home based care referral<br><br>- Transfer out referral | - There is integration of services. Clients are referred from counseling and testing to clinicians (ART clinic) for further management. Clients may be referred from home-based care to HTC. At ART clinic clients may be put on CPT or ART depending on health status. Sometimes clients are referred from the ART clinic to KCH or home-based care using referral forms. ART and home based care clinics and HCT work jointly. Clients are also referred from HTC and ART clinic to other facilities of client's choice. | - Ability to screen and refer TB and STIs for ARTs.<br><br>- Help patients access varied services.<br><br>- Authentic enough for acceptability.<br><br>- There is a mechanism within lighthouse for following up referrals to KCH and communities within their catchment areas, but not to other facilities (use nurses and volunteers).<br><br>- The center sees 9,500 patients per month, including about 6,700 people on HAART since inception. | - Lack of coordination between the referral source and referral al destination. There is no back referral in place.<br><br>- Poor documentation of referred cases.<br><br>*"People may be referred for example from MACRO but the referral form bears no official stamp, may just write reactive. This is not authentic, so we do a confirmatory test which brings in double counting and provide untrue picture of results to NAC/HMIS."*<br><br>- Poor documentation of referrals. In health centers, they don't have a register for referrals.<br><br>- Shortage and frequent changes of staff at KCH affect back referral.<br><br>- Increased workload for staff prevents staff from documenting referrals at | - ART program is a complex program. Therefore, follow up on drug adherence is essential.<br><br>- Follow up system in the community is very important as it contributes to drug adherence.<br><br>- Integration of services has contributed to effective referral for a wide range of services. |

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| | | | | | times. |
| MSH | - CT site service to service referral<br><br>- Internal client referral<br><br>- Outreach referral | MSH follows the MoH and Lighthouse systems of service to service referral. MSH employed counselors at the facility level to provide HTC services to clients and may refer them to clinicians within the facility using the CT site service to service referral. Sometimes clinicians refer clients to HTC to determine serostatus and provide care accordingly using internal client referral.  MSH also engages Expert Clients at the district hospital in HTC and MIP. Expert Clients at times walk with the patient to another point of service. These also refer clients to services. They are placed at under five clinics and paediatric wards.<br><br>- Outreach referral mainly is from support groups to facility or facility to HBC. | - Most of the referred patients within the facility access the services because of the counselors who direct them to the next service.<br><br>- This has increased number of children tested for HIV from 9-80 per month. | - There is no mechanism for following up referrals. *"We don't know whether referred clients accessed the service or not"*.<br><br>- Lack of coordination between clinicians and counselors or Expert Clients. *"*When counselors/ Expert Clients *have referred clients to clinicians, we don't see them back"*.<br><br>- LTFU is high. | Despite resource constraints, MSH achieved much, largely due to enhanced coordination. |
| Dignitas | - Community to facility referral<br><br>- Facility to facility (facility to district hospital)<br><br>- Facility to community | Referral forms are provided to CBOs who refer clients to a health facility through the HSAs. The facilities also have forms to refer clients to a district hospital.<br><br>Clients are also referred within the facilities/hospital from one service to another.<br><br>- There is also a form for tracing clients. | -  They have a mechanism for following up referrals especially from the community to health facilities to district hospitals. Health facilities in charge follow up referrals to district hospital.<br><br>- They placed a collection box/pigeonhole to keep all the referrals at the facilities and the hospital which are collected by the health center | - Documentation of referrals at the facility not done frequently.<br><br>- No of referrals do not correspond to actual referrals seen at the hospital.<br><br>- Clinicians do not complete information on the referral form; either they leave some spaces blank or not write anything at all. | - Referral from the community level to health facility/hospital has improved health outcome for several clients because of timely referral.<br><br>- This has strengthened community partnerships for health. |

| | | | in- charge.<br><br>- The referral has a section for management feedback and other relevant information which can be provided.<br><br>- The proportion of women supplied with nevirapine increased, the proportion of women put on CPT increased and defaulter tracing of mothers on ART also increased during post-intervention period. | *"Sometimes the feedback part is not filled even when they have assisted the client."*<br><br>- Supply of referral form is erratic. | |
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| BRIDGE ll | - People and paper base referral | Community referral agents (CRAs) refer clients to health facilities for all health issues, including HIV and to other social welfare services for issues of OVC and violence of all forms. They keep all the copies of referred cases. Staff at the health facilities/other social welfare services document referred cases and give feedback to the CRAs. The CRAs collect referral forms from the service providers and check with the copy left behind.<br><br>They find out whether clients accessed the services or not. If not they are referred again. | - Total of 18,774 referrals, 41% of clients referred for HTC are men, 7% of clients referred for HTC are couples.<br><br>- Model has improved referrals and coordination between different organisations providing HIV related services.<br><br>- Referral system has contributed to establishment of new support groups.<br><br>- ART default rate has reduced.<br><br>- Referral system has contributed to reduction in optimistic infections due to improved care. | - Some health care providers disregard referral forms. *"Use of referral forms is treated as an extra work."*<br><br>- A recognisable number of referred clients are sent back by service providers without proper explanation.<br><br>- Poor coordination between health service providers and CRAs.<br><br>- Traditional beliefs acting as a barrier to health seeking behaviour.<br><br>- Shortage of medical supplies in health facilities impedes provision of services and results in disappointment of | |

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| | | | referred clients.<br><br>- There are few service providers for example for HTC<br><br>- Sustainability is a challenge since CRAs are paid a stipend.<br><br>- Challenge of reporting on referrals. For example, mentors report on the last day of the month but those who are referred towards month end may not be depicted, thus presenting a false picture that they did not access services. | | |
| PIH | - CT site to services referral<br><br>- ART & home-based care referral.<br><br>(Adapted from Lighthouse). | Clients are referred from counseling and testing site to Moyo clinic for assessment. Based on outcome, they may be referred to ART clinic and home-based care. | The referral mechanism is functional in the sense that services are closer to each other and clients really access the services. The referral form has all the necessary care attributes.<br><br>The HTC sites register all the cases referred to the clinic. They check data with the clinic to confirm whether or not clients they referred were assisted. So far most clients comply with the referral. In very rare circumstances do clients opt for other clinics; either because there is a person they know at the clinic or they are not ready to start | There are no weaknesses or challenges that were encountered except for some clients who disregard the referral. | Referrals ensure quality care for clients. |

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| | | ART. | | | |
| MoH | - Community to facility<br><br>- Facility to facility (facility to district hospital)<br><br>- Facility to community<br><br>- Referral within facility<br><br>- External referral | HSAs refer clients from the community to health facilities and complicated cases are further referred to district hospitals by clinicians and then to central hospitals, if need be. Through established networks like CBOs MoH refer clients to CBOs for HBC. Within a facility/hospital setting there is active referral between services. For example, the OPD filters clients to ANC, family planning, HCT, etc.<br><br>- At each referral point except for referrals within the hospital, there are referral and back referral forms. Sometimes a health passbook is used to refer clients.<br><br>- Clients from central hospitals may be referred further by the Director of central hospital to private hospitals depending on their conditions.<br><br>- If the condition cannot be managed at the private hospital the patient may be referred to a hospital outside Malawi by the Director of preventive clinical services following recommendations of a medical committee, which applies criteria such lack of highly specialized medical equipment for diagnostic purposes and medical expertise to manage the medical cases, complicated cases deserving hospital monitoring and | - The health profile books play a great deal in referrals because clinicians are able to follow trends of patients and receive appropriate treatment.<br><br>- The referrals are free of charge and patients know that they will be assisted. | - Hospitals and health facilities are few and often far apart causing referred cases not to comply with referral instructions.<br><br>- At community, facility and district levels, health care personnel are few and overstretched resulting in lack of follow up of referrals. Besides, they are not motivated and at times not well trained.<br><br>- The back referral system is not functioning due to the above reasons.<br><br>- Clients are often lost as they move from one service point to another. "*Within the facility/hospital clients are lost out when referred from one point to another either they have lost the directions and are not comfortable with asking since our signs are in English*".<br><br>- Poor documentation of referrals. "*Most facilities do not keep complete records in terms of how many have been referred and therefore unable to provide complete service* | Feedback for referral is important because it provides further information to the referring source for example; the referring clinician may know how to handle a similar case in future. Further the referring source may want to know the outcome of the case. |

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| | | specialist attention requiring sophisticated hospital procedures and emergency medical cases beyond central hospital's case management ability. | | - Free health services are heavily abused. The system doesn't have a mechanism to check service recipients and frequency. *"A person may have several health passports and access care at different health facilities and collect drugs."* | |
| CHAI | - Referral within facility through a client walk –in system | Expert Clients take a client from service to service. This is called walks/linkages. One client may be referred from under- five to HTC and the Expert Client at under- five clinic walks with the client, hands her/him to a fellow Expert Client at HTC. An Expert Client is stationed at each unit within the health facility. Defaulter tracing is done by community volunteers and HSAs through a register and a mobile technology application. Expert Client at the health facility sends names of clients who did not honor their appointments to the senior HSAs who distribute the names to HSAs based at the client's community The HSAs contact the volunteers, also known as health workers, for tracing. | - Almost everyone referred to a service access the service because of the walk in strategy. - Expert Clients motivate clients and encourage adherence and retention in care. | - Clients are too many to be followed up by Expert Clients. Therefore, HSAs and volunteers in the communities are involved in follow up. - Health facility staff attitude not supportive of Expert Clients' work. | Referrals through the use of Expert Clients improves uptake of services. |
| MSF Belgium | Facility-to-facility referral | Patients are initiated on ART at a health center and referred from the health center to a health post in their | - Reduced LTFU because clients are managed right away in their community. Defaulter | - A back referral mechanism put in place but not | Referring clients to their community health posts has reduced congestion in |

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| | | communities. Master cards are left at the health facility and only a copy is given to the clients. | rate is 11% in the ART program.<br><br>- Increased access to services as clients are referred to their community health post. | functional.<br><br>- MSF used to supply referral forms to the DHO but stopped when they transferred this responsibility to the DHO as part of their transition plan. The DHO is unable to supply the forms and therefore they are not in use.<br><br>- Staff not motivated to use the referral forms.<br><br>- Limited resources to print referral forms for all the facilities and health posts prohibiting usage. | health facilities and the district hospital leaving the hospital to attend to delicate cases only. |
| PSI/PACT Malawi | -Community based referral model<br><br>- Health facility referral mechanism | At the community level, the focus is on linking with CBOs including support groups and NGOs working with HIV, which District AIDS Coordinating Committee is responsible for coordinating. In cases in which the client's status is unknown all providers (CBOs, NGOs) etc. refer clients to health facilities for HTC services. HTC services are the point of entry into the continuum of care for PLHIV. The tools used in this model include the HTC Referral Form in duplicate, (one copy of this form is retained by the referring organization with the second copy given to the client to take to the receiving organization), a General Referral Register located at and | - There is increased number of people getting tested for HIV<br><br>- Referral mechanism eases tracking of clients because of the back referral and follow- up and r reduces loss to follow-up.<br><br>- Provides assurance of continuity of care for clients.<br><br>-  Documented referrals have improved internal referrals within health facilities, for instance from HTC to ART to FP and vice versa.<br><br>- Referral model and tools have been adopted by Banja La | - At CBO level, staff don't work as a team. The person trained assigned to handle referrals only focuses on collecting data and if not available, no one else does hence the possibility of losing some information and data at the health facility.<br><br>- Partner organizations are using different forms. Coordination becomes difficult and sometimes data are missed. One partner is interested in data that others don't care about, hence reduced motivation to collect. | |

| | | completed by the Referring Organization and a Receiving Referral Register located at and completed by the Receiving Organization. The provider at the Receiving Organization is responsible for placing the HTC Referral Form in a cardboard box provided by the Network Coordinator. This box serves as a central repository for all referral forms received by the organization. The project Officers from partners at the end of the month collects all the forms. In cases when clients know their status or are seeking support services for people affected by HIV and AIDS, particularly support for orphans and vulnerable children (OVC) a program person at each network member will make a referral to the appropriate providing organization using a general referral form which is also filled in duplicate and the same procedure is followed. | Mtsogolo and Matiki Health post in Dwangwa.<br><br>- Because the referral mechanism includes other social services, there is increased openness about gender violence issues.<br><br>- Improved quality of services because of capacity building. | | |

**Involvement of Expert Clients**

Community volunteer workers are referred to variously by different organizations as Expert Client (CHAI, Dignitas, MSF Belgium, PIH, and MSH), community health worker (Baylor, CHAI), mentor mothers (MSF BELGIUM, M2M), community activists (Dream Center), and community referral agents (BRIDGE ll) and volunteer (PSI/PACT Malawi and Lighthouse). Mentor mothers and activists are a category of Expert Clients since these are HIV positive individuals. The study focused more on Expert Clients. Most of these Expert Clients provide a link to care and support services for PLHIV between the community and the health facility.

Expert Clients are chosen based on criteria developed in consultation with the community and the implementing organizations as listed below:

1. Ability to read and write in English. Junior Certificate Examinations is preferred. Others exclude English but admitted that such volunteers have difficulties completing the forms and providing accurate data
2. Ability to keep confidential information
3. Individuals who have disclosed HIV status
4. Individuals who adhere to treatment
5. Preferably mother who benefited from PMTCT services and followed the principles of the PMTCT program
6. Outgoing, outspoken, easily connected with people
7. Physically well enough to work during clinic hours
8. Involved in volunteerism through support groups, CAG and is willing to work as a volunteer
9. Motivated and committed to being part of the multidisciplinary team with the clinic
10. Self-selected but approved by the community
11. A person who is compassionate
12. A NAPHAM member/member of a support group
13. One who is reliable
14. A person who respects himself/herself and respects others

Some institutions, like Dream Center, preferred women, men and youth to support different people effectively.

Their roles/job descriptions differ depending on program design. Some organizations do not have a written job description because Expert Clients are not employees (Dream, MSH) but they develop work plans and advice the Expert Clients on what they are supposed to do. In general, most of the key tasks of the Expert Clients include the following:

1. Identifying clients and do needs assessment for the clients
2. Conducting health education talks on a wide range of topics such as HIV counseling and testing including couple counseling and testing, the basics of HIV prevention, treatment and care, support services, general services for health and wellbeing, family planning services, PMTCT and mother-infant pair follow up.

3. Refer clients for various services
4. Walk clients from one service to another for example escorting patients from PMTCT to ART if initiation of ART is required
5. Follow up clients that have been referred/defaulter tracing of clients
6. Compile and submit monthly reports to the District Health Officer and to organizations supporting them.
7. Share the reports with other community structures including Village AIDS Committees, Community AIDS Committees, Community Action Groups and respective government offices.
8. Assist in formation and management of support groups.

The working base for Expert Clients varies from one organization to another. In some organizations, Expert Clients are based both at the health facility, district hospital, health post, and in the community (CHAI, MSF Belgium and Dignitas), while in others they are based at the health facility only (MSH). At Dream, the activists are based in the communities only but linked to health facilities to facilitate follow- up of clients and referrals. Further, they are placed at strategic places within the hospital or facility setting. Some, for example, are placed at the HTC site, others at ART clinic, and some at paediatric ward or antenatal clinic/PMTCT site, depending on the program focus.

Training of Expert Clients was tailored to suit the primary focus of each organization. Most organizations trained their Expert Clients for five days including practicum sessions. In all cases a training manual was used by the trainers. Expert Clients are provided with job aids ranging from resource manuals to flip charts, laminated handouts, leaflets and local games.

**Routine duties of Expert Clients**

Most Expert Clients work three to five days a week. Some spend specific number of days at health facilities following activity schedule of the clinic and the other days are spent in communities following up clients, defaulter tracing and offering health education talks. In some organizations all five days are spent at the hospital/health facility because other volunteers are assigned to follow-up clients and conduct defaulter tracing. Each organization provides a set of data collection tools for their use. The tools include government of Malawi register, monthly reporting forms highlighting indicators, and referral forms.

Most Expert Clients are not paid for their services, but receive a stipend to cover for their transport costs and lunch. The amount varies from one organization to another, but range from K5,000 to K 14,000 per month. Different incentives are also provided which include T- shirts, identity card, bicycle, uniform and an allowance during quarterly meetings. In some organizations Expert Clients are given stipend only and no other incentives. For additional information on the work of Expert Clients and other volunteers refer to Table 3 below.

Table 3: The work of Expert Clients and other community volunteers

| Org. | Training | Routine work | Expert Clients/Volunteer remuneration | Attrition | Impact indicators | Exit strategy |
|------|----------|--------------|----------------------------------------|-----------|-------------------|---------------|
| DREAM | Training was done for 5 days for the activists (classroom based). Topics include; HIV, TB, OI, PMTCT comprehensive, treatment, care and support. They did not use a training manual but information from books. | Activists are given job aids but were not shared with CRS. Dream doesn't have a written job description but agree verbally what their job entails. They normally work for 5 days based at Dream Center but also work in the community | - Activists are given K600.00 per day they aidswork. - Sometimes they are given food. Dream could not determine cost per volunteer per month. However one beneficiary cost $ 300 per year. | Turnover is low | - Reduced LTFU - Many people who were sickly are now active - Increased knowledge and information on PMTCT & HIV in general | Dream has indefinite time so as long as funds are available, activists will continue their work. |
| Baylor | 7 days classroom training and 6 months on the job training for the community health workers (CHWs). The training topics were as follows; PMTCT, Paediatric ART, EID, TB, malaria, ARTs and side effects, drug adherence, follow up and report writing. A manual was used for the training. | Job aids were available but were not shared with CRS pending on approval. CHWs are based in the community and work for 5 days. They are attached to health centers. | - CHWs receive K15,000 per month but if they are trained as HTC counselors, they get K23,000 per month. - Other incentives include airtime, bicycles, raincoats &stationery. | Very low. Only 2 left since inception of the program one found a job while one went to school. | - Increased uptake of services | The program will be handed over to MoH since the CHWs are just like HSAs |
| Lighthouse | Home based care volunteers were trained for 14 days. The training was classroom based but included practicum. Volunteers were trained in HIV and AIDS basics, TB, Mobilizing communities, communication, counseling, gender, and management of chronic illnesses, infection prevention, nutrition, living positively &treatment adherence. | Volunteers are given job aides (but were not shared with the team). There is no written job description. They work for five days. Volunteers are based in the community but they also work at the center based on schedule and shifts. | Volunteers get K650 as transport per day Other incentives include the following: - Volunteers on ART don't queue when they sick, they are given a priority. - Volunteers are given umbrellas, | High because of lack of monetary benefits. Survival is a priority being in town. They had over 500 volunteers but about 300 are | Not possible to get exact data but no of clients knowing their status, number of HBC clients on ART, number of clients on ART is increased | Based on volunteerism. Issues of exist do not arise. They are self-selected, no one forces them. |

| Org. | Training | Routine work | Expert Clients/Volunteer remuneration | Attrition | Impact indicators | Exit strategy |
|---|---|---|---|---|---|---|
| | A manual was not used; instead they relied on experts in the field to train. | | - Provided with lunch allowance during training<br><br>- Learning visits to other districts | active. | | |
| MSH | HTC counselors were trained for five days and Expert Clients for three days. These were trained in HIV and AIDS basics, PMTCT, paediatric HIV, DBS, HTC, referrals, nutrition and communication. HTC counselors' training included practicum on HTC and DBS. MSH doesn't have a manual but the volunteers were trained by Baylor. | HTC volunteers and Expert Clients have no job aids but have a written job description which was also shared with CRS.<br><br>Both work for five days. Counselors are based at a health facility and Expert Clients at a district hospital. None are community based. | Counselors get K12, 000 a month and Expert Clients get K 10,000 a month (K500 a day as lunch allowance). No additional benefits are offered. | Not high | Have contributed 30% of clients tested in Malawi for the 8 districts they are working in.<br><br>Increased uptake for PMTCT services. | Counselors will be absorbed by other NGOs if possible. MSH will discuss with MoH the possibility of absorbing them. MSH is not sure for the Expert Clients. |
| Dignitas | Three days for the Expert Client on specialty of care. It was classroom based. The topics included: Role of Expert Clients, HIV and AIDS, treatment, care and support, treatment adherence, positive living, PMTCT, paediatric care and communication skills, stigma and disclosure, referrals and record keeping and report writing.<br><br>Dignitas used a manual for training. This was not shared with CRS but | Expert Clients use job aids which are available. They work<br><br>Four days a week. They are based at two selected health facilities and Zomba district hospital. | Expert Clients receive K9,000 a month. Other incentives include bicycles and T- shirts bought once for the program. | Very low. 2 left, 1 found a better job, 1 resigned voluntarily because he absconded from duty for 1 month | - Increase uptake of services.<br><br>- Loss to follow up was reduced due to defaulter tracing<br><br>- Male involvement has improved<br><br>Number of support groups has increased with the work of | No plans yet in place. They depend on donors as they write proposals to support the work of Expert Clients. The assumption is that MoH may take over if they happen to |

| Org. | Training | Routine work | Expert Clients/Volunteer remuneration | Attrition | Impact indicators | Exit strategy |
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| | was requested. | | | | Expert Clients | phase out. |
| BRIDGE ll | CRAs were trained for five days in caring for the carer, effective communication, CRAs roles, HIV prevention, care and treatment and psychosocial support, stigma and discrimination, TB and HIV, nutrition, vulnerability, barriers to health, sexual and reproductive health. A training manual was shared with the team. | CRAs use job aids and have a written job description. Except for the job description, job aids were not shared. They work for three days per week -- two days in the community, one day at the facility | CRAs get K5,000 per month (K500/day for 10 days they work in a month).<br><br>- T-shirts and IDs are provided as other incentives for motivation. | No problems have they encountered with volunteers dropping out | - People appreciate the outcome of referral.<br><br>- Chances of clients accessing the services are high | They are working with district officers from various ministries to take over. |
| PIH | Site coordinators were trained for three weeks while Mentor mothers were trained for 10 days. Topics for mentor mothers; HIV/AIDS basics, ART, PMTCT comprehensive, positive living. Site Coordinators in addition to these, they are trained in management skills, supervision, conflict management and report writing. Used trainers manual and participants manual. | They all work for five days in a week. They are based at health facility, district and Central hospitals for both government and CHAM. The ratio is 1:10 (1 mentor mother to 10 HIV positive women per month) | Mentor mothers receive K7,000 per month on contractual basis of 1 year. After 1 year they reapply. If they were performing well they continue, if not they graduate. Site Coordinators receive K14,000 per month on permanent contract. They are appraised and remunerated according to performance. | The attrition rate for mentor mothers in the city is high because they say that salary is low. | Contributed to increased service uptake on infant testing, CPT, PMTCT prophylaxis, ART and CD4 testing and results. | Initially the plan was that they will be absorbed by MoH as HSAs but most of them do not qualify because of education status. Additionally, those that qualified could not join the system because there were no vacant positions. When program |

| Org. | Training | Routine work | Expert Clients/Volunteer remuneration | Attrition | Impact indicators | Exit strategy |
|---|---|---|---|---|---|---|
| PIH | The training was for 5 days for volunteers at Moyo clinic and Expert Clients who are selected through HBC program. These were trained using a manual and the topics included; positive living, safer sex practices, partner disclosure, nutrition, PMTCT, ART management, adherence and side effects. | Volunteers have job aids and job description in Chichewa (only the job description was shared) Volunteers are based at Moyo clinic and Expert Clients are community based, selected through HBC program.<br><br>The volunteers and Expert Clients do not have specific days for assisting clients but are given a target of 20 clients for one volunteer and six clients per Expert Client per month. Expert Clients only come to the center for the quarterly review meetings. | Expert Clients and volunteers are not paid. However, they are given K2000 during the quarterly review meetings. They also receive T-shirts and IDs.<br><br>- Each HBC is given a bicycle | Low. Some of them are sick and do not perform so they are replaced | Increased number of clients | Project is phasing out in May this year. It is assumed that the volunteers will continue to work with the CBOs. Clients will be informed to access services direct from the clinic. |
| CHAI | Expert Clients were trained for five days and community health workers for two days. The training for Expert Clients focused on role of Expert Clients, HIV and AIDS, basics, treatment and care, ART management, treatment of OIs, positive living, PMTCT, pediatric care and treatment, basic communication and counseling skills, stigma and disclosure, follow ups, referrals and record keeping and linkages to community support services. The community health workers were mainly trained in defaulter tracing, communication | Job aids for Expert Clients are available and were also shared with CRS. Expert Clients work for 5days per week and community health workers depends on the load they have to follow up clients.<br><br>Expert Clients are facility and hospital based while community health workers are community based. | Expert Clients get K8,000 per month. They also receive uniforms, bicycles, stationery and allowances during meetings<br><br>The program used 5.7 million kwacha for 50 Expert Clients including training. | Very low. Out of 50, only two left. One passed away while one relocated to another area | Increased number of new patients, increased number of counseling sessions, increased number of Children receiving DNA-PCR tests and increased number of linkages | No clear plans. Negotiating with partners like CRS to take over. |

| Org. | Training | Routine work | Expert Clients/Volunteer remuneration | Attrition | Impact indicators | Exit strategy |
|---|---|---|---|---|---|---|
| | skills and report writing. A training manual is available and was shared with CRS. | | | | | |
| MSF Belgium | - Mentor mother's training is for 14 days, classroom based and practicum. Expert Clients were trained for 5 days, (3 days classroom-based and 2 days of practical). The training focused on HIV and AIDS basics, nutrition, STI, TB, condom use, ART, Family planning and HTC. A training manual is available but was not shared. | The volunteers have job aids and job descriptions which were also shared). They work 5 days per week.<br><br>- Mentor mothers are based at the district hospital and health center Expert Clients are community based. | Expert Clients and mentor mothers receive K12,500 per month. They are paid by DHO. They are also provided with T shirts and lunch allowance during meetings. | None. Those that fail during assessment are dropped down | Partner testing has gone up<br><br>Uptake of PMTCT services has increased and DBS | Will be handed over to government. |
| PSI/PACT | 5 days training for the volunteers (, classroom based and included practical sessions). The training focused on<br><br>HIV and AIDS basics, STI, condom use, HTC, communication, referral, and infection prevention, ethics, M&E and behavior change. PSI/PACT Malawi used a training manual but was not shared with CRS. | Job aids are developed depending on nature of campaign. Each partner organization develops work plans for the volunteers. Copies were not shared.<br><br>They don't have specific working days but are flexible to conduct sessions according to the plans they have with partners.<br><br>Volunteers are community based | Volunteers are not paid staff. They receive lunch allowances when they work with partners based on partner's rate.<br><br>They are provided with bicycles to aid mobility. | Not very worrisome. Transfers and change of stay are reasons for those that have left | Data available but not accessible | None, these are community based and will continue working |

**Supervision processes**

Expert Clients based at the district hospital are supervised by HTC coordinator, PMTCT Coordinator and ART Coordinator, depending on where they are located. At health facilities, the health facility in charge or the HSA supervises the Expert Clients. In some cases partners supervise the Expert Clients through designated staff employed by them.

Most organizations use a supervision check list to conduct supportive supervision. Others include a requirement for observation of the Expert Clients as they perform their duties. Progress is assessed through reports generated on weekly/monthly/quarterly bases. Feedback is provided to them through their monthly or quarterly review meetings.

**Barriers to the work of Expert Client and others volunteers**

Despite discussing expectations with the implementing organizations at the point of engagement, Expert Clients and other volunteers still have high expectations in terms of financial and other benefits. This affects their motivation and ability to perform their duties. Surprisingly, apart from Lighthouse, attrition is low for all organizations. MSF Belgium Program Manager said, "*When Expert Clients were selected other volunteers stopped to work voluntarily because others were receiving something."*

Other challenges include the fact Expert Clients have created high demand for the HTC services but there has been shortage of test kits. Shortage of supplies and test kits hinder provision of services. Respondents also noted that space in hospitals is a challenge. Expert Clients are forced to work in unsuitable corners where privacy is questionable. In addition, the pre ART program has not yet been fully implemented from national level. In some cases clients do not trust Expert Clients working in the hospitals/facilities because they do not have identity cards. Expert Clients with inadequate literacy levels often produce poor quality documentation and/or inaccurate data and require further training and support.

Respondents also highlighted an important risk to Expert Clients themselves in terms of exposure to infection. The Program Manager for CHAI said, *"Two had TB and were admitted. Fortunately they recovered and this made us review our entry points to exclude the TB ward."*

Finally, several respondents indicated that the attitude of health staff in some health facility is not supportive of volunteer's efforts or dismissive of Expert Clients. This in- turn contributes to volunteer turnover.

Organizations employed several strategies to address the above constraints. For example, some partners assisted Expert Clients and other volunteers to develop realistic work plans. In some instances, partners reduced Expert Clients' level of effort to 3 to 4 days a week. Some organization also use duty roster so that Expert Clients and other volunteers work in rotation. Other ides included organizing monthly meetings to discuss progress, challenges encountered and way forward to boost morale. Some provide yearly contracts to Expert Clients allowing the partner to discontinue some Expert Clients who are underperforming and recruit new ones.

This provides equal chance for others to join the multidisciplinary health team. Partners also highlighted the importance of providing refresher training every year and providing stress management activities such as trips to entertainment places like Salima, to reduce burn out.

**Benefits of using Expert Clients**

There are several obvious benefits of using Expert Clients in programs. The following benefits were mentioned by interviewees.

- Promotes interactions with the rest of the community: Country Manager for M2M said, "*Because they are community members, clients are free to talk to them whether at facility or at home than hospital staff*".

- Lighten the load on an already overburdened health care system: Responsibility for health education has shifted from health workers to Expert Clients, thus reducing workload and allowing them to focus on patient care.

- Additional support: Expert Clients have more time to give support and information to clients than hospital staff considering the long queues in the facilities.

- Sharing personal experience: Because Expert Clients speak from personal experience, clients believe them. Organizations have observed higher levels of partner disclosure and service access in areas using Expert Clients.

- Complete continuum of care for pediatric HIV care: Expert Clients have time to ask about the whole family and may help identify exposed children who have not been picked up by the health facility.

**Lessons learned**

Respondents shared key observations relating to their experiences working with Expert Clients.

- Expert Clients are a valuable cadre that can strengthen the health care system.

- Problems affecting clients are solved better when you involve Expert Clients because they share much in common.

- Expert Clients without pay or other financial benefits do not work effectively, they need to be motivated.

- When clients get referral, it rises up their expectations that they will be served as a priority yet the health facilities won't provide preferential treatment to them as they follow procedures, which may require them to prioritize very ill patients. This tends to discourage clients on referral.

**CONCLUSIONS**

Although most of the referral systems reviewed during the study seem to be functional, they do not work optimally. As a result clients may be lost to follow up because of gaps in the system. Shortage of staff, especially failure to designate persons to follow- up referrals by most organizations presents a potential gap in the service delivery system. Organizations like Dignitas, BRIDGE ll and PSI/PACT Malawi have established strong referral systems and made significant progress in service delivery largely due to their efforts towards closing the gaps in service delivery and assuring continuity.  Certainly, there is need for further improvement on existing referral systems and approaches for engaging with community volunteers. There is need to deploy strategies that will strengthen the use of back referral forms. The training curricula for health professionals should emphasize a two- way or closed- loop referral model so that staff get used to this right at the point of training.

Expert Clients are a valuable cadre that can strengthen the health care system. It is important to sustain the work of Expert Clients at facility and community level. Therefore, tackling existing challenges should be a priority concern for all implementing organizations in order to improve the care and treatment outcomes for most clients and ensure that they remain in the continuum of care.

The findings of this study are extremely important and will inform the design of a national referral mechanism to be developed by MoH in consultation with key stakeholders and the design of future programs that plan to engage community volunteers, particularly Expert Clients.

**Appendix 1: Data Collection Tool for Referral Mechanism**

1. Background information
    a) Organization name and mission
    b) Geographical focus
    c) Health/HIV and AIDS Project details: goal, objectives, time frame, funding level, partners, participants/audience, primary interventions
    d) Health delivery model (MoH only)
    e) Key policy issues on referral (MoH only)

2. Referral model
    a) What's the name of the referral model you are using on your health/HIV and AIDS program?
    b) How was this referral model developed? Was it adapted from another project (which one and how) or developed specifically for this project (describe process)?
    c) What is/was the aim for the referral model?
    d) What is the scope of the referral model (HIV, all health, other social services, etc.)?
    e) Referral Mechanism
        i. Description: Do you have a document that describes your referral model/mechanism? (Provide description verbally and any write- up for reference)
        ii. Diagram: Do you have a matrix that captures the referral model you have described above? (Please provide a copy if exists.)
        iii. Verification that client received service: How does your program know that referred clients have visited and received services at the places they are/were referred?
        iv. Supervision/Management:
            • Is there a mechanism for following up referrals? Who does that and how is it done?
            • Describe the modalities for supervising the entire process of referral from issuance of a referral to delivery of a service and beyond?
        v. Data collection tools: Do you use a referral form? (please provide a copy) Do you use any data collection tools to document referrals? (please provide copies)

    f) Referral Personnel:
        i. Volunteers and staff: Who in your program issues referrals to clients? Is it volunteers or staff? Who in your program supervises them?
        ii. Selection criteria: How are the staff issuing or managing referrals selected?
        iii. Training requirements and materials: What training do the staff issuing or managing referrals receive? Who provides the training? Is it a one off or continuing training? (Over what period?)

   iv. Workload (hours per week): In general, how many hours per week do these staff and volunteers work? What proportion of their time do they spend on issuance and follow up of referrals? How does your program track the time these volunteers spend on the program?

   v. Remuneration (if any): Are your volunteers paid? How much per week do you pay? What other benefits do they receive?

   vi. Burnout/turnover:
- What do you do to ensure that the volunteers are not overstretched/overburdened by the work they do? Do the volunteers experience burnout? How do you address burn out among your volunteers?
- How do you manage to retain the volunteers? Do you have a documented strategy for handling retention and incentives for volunteers? (Please describe or provide a copy.)

   vii. Linkages to other structures (CHBC, Support Groups, etc.): How does this project relate to other projects within your organization? How does the referral mechanism for this program relate to those used by other projects within your organization?

3. Evidence to support model:
 a) Cost estimate per beneficiary
 b) # referrals per quarter/year by type of service by sex (as compared to baseline)
 c) Proportion of those who actually received services – compare data for the year before and a year after installation of the referral mechanism
 d) Other Impact indicator data reflecting effectiveness of the referral mechanism
 e) Sustainability/transition plans/exit strategy – how mechanism will be managed when project closes
 f) Strengths and Challenges of the referral mechanism
 g) Lessons learned
 h) Assessment: Has the referral model been assessed? Provide any findings.

**Appendix 2: Data Collection Tool for Expert Clients**

1. **Background information**
   a) Organization name and mission
   b) Geographical focus
   c) Project details : goal, objectives, time frame, funding level, partners, participants/audience, and primary interventions

2. **Use of Expert Client**
   a) What are the selection criteria for Expert Client that you use/d in your project?
   b) Are your Expert Clients trained? In what specific areas or topics are they trained?
      - Do you have a manual for training Expert Clients? (Do you mind sharing a copy?)
      - How long does the training take?
      - What does the training involve? (Classroom sessions, practical sessions or both)
      - What kind of job aids are the Expert Clients using? (Do you mind providing copies?)
   c) How long have you been working with Expert Clients as an agency? How long have you engaged them on this (particularly) project?
   d) What are the key tasks for the Expert Clients? Do you have a job description for Expert Clients? (Do you mind sharing a copy?)
   e) Are the Expert Clients involved in other activities such as CHBC, Support Groups, etc.? In what way/s are they involved? What do they do?

3. **Services offered by Expert Clients**
   a) Are the Expert Clients based at health facilities? What is their entry point (primary base) at a health facility? (This could be a particular unit such as under 5 clinic, ANC clinic or PMTCT clinic etc.)
   b) How is their work organized at the facility? Do they have a job description specific to health facility activities? (Do you mind sharing a copy?)
   c) How is follow up for patients done at health facility level? How is it done at community level? Do Expert Clients have a tool to aid their follow up of clients? (If so, do you mind sharing a copy)
   d) How many days or hours per week do the Expert Clients work? How many of these days are spent at the health facility?
   e) What tools do Expert Clients use to record information regarding their services/work?

4. **Support for Expert Clients**
   a) Are the Expert Clients paid for their services? What is their remuneration package?
   b) What other kind of support or incentives do you provide to the Expert Clients to motivate them?
   c) Who supervises the Expert Clients at the health facility? Who supervises them at community level?
   d) What tools do the supervisors use? (Do you mind sharing copies with us?)

e) What do you do to ensure that the volunteers are not too stretched/overburdened by the work they do? Do the Expert Clients experience burnout? How do you address burn out among your Expert Clients?

f) How do you manage to retain the volunteers? How do you deal with attrition (or drop out) out among Expert Clients? What are some reasons why Expert Clients decide to leave the program? Do you have a documented strategy for handling attrition among Expert Clients? (Please describe or provide a copy.)

5. **Evidence to support model**
   a) What is the cost estimate per beneficiary?
   b) Impact indicators data
      i. What indicators do you use to assess the performance of Expert Clients? (Do you mind sharing a list?)
      ii. What is the progress so far on these indicators?
      iii. Could you provide data on the following indicators:
         - # referrals over specified time period by type of service by sex (as compared to baseline)
         - Proportion of clients who actually received services one year before installation of Expert Clients and one year after (could use 6 months if project has not been in place for more than a year.
         - Estimated reduction in LFTU (could use data for the period 6 months before and six months after Expert Clients were installed).
   c) What do you perceive to be the benefits of working with Expert Clients?
   d) What barriers affect the work of Expert Clients?
   e) How do you address these barriers in your project?
   f) What are your exit plans for Expert Clients? What do you plan to do with the Expert Clients when this project ends? Are there plans to transition them into a different role? What would that be?
   g) What lessons have you learned through this work with Expert Clients?

## Appendix 3: Organizational characteristics

| Name of org. | Partners | Mission | Goal | Objectives | Interventions | Geographic focus | Timeframe |
|---|---|---|---|---|---|---|---|
| Dream | Word alive, CHAI, MoH | Not provided | To increase access of PMTCT services in Malawi | To promote uptake of PMTCT services, to care care of HIV positive pregnant mothers, to follow up babies born from HIV positive mothers up to 18 months, to provide support in home based care for those with problems | PMTCT oriented program and IEC | Balaka, Dedza, Mangochi, Machinga, Dowa, Mzimba and Blantyre | 2005-indefinite |
| Baylor | Ministry of Health, Light house & UNC | Take care of HIV positive women and exposed and or infected children to enhance quality of life | To improve access of ART services for mothers and children | To increase access to PMTCT services, To increase paediatric access to ART and mobilize communities on HIV prevention | Paediatric ART, PMTCT, community mobilizations on behavior change, & Outreach clinics | Mzuzu, Blantyre Zomba & Lilongwe | Started in 2004 and it is open ended. Tingathe program started in 2008, phasing out in 2013 |
| PIH | MoH, CHAM, NAC, Lighthouse, USAID, UCLA Program in Global Health, Baylor College of Medicine Malawi Children's Fund, and EGPAF | To have a significant impact on the HIV/AIDS epidemic in Malawi and the lives of individuals infected and effected with HIV in a way which brings glory to God and demonstrates Christ's love in word and deed". | To achieve a high- rate of retention in care in those areas where the program operates. | To provide quality HIV services in support of the national ART strategy, Strengthening the skill of health care providers in HIV/AIDS care, and developing a consortium of sites for operational research. | supporting HIV care for over 60 organizations in Malawi, provide HTC services, in hospital care for clients and provision of free ARTS and systems mentoring to improve PMTCT, EID, pediatric care, | Lilongwe & Mzimba | 2010- 2015 |

| Name of org. | Partners | Mission | Goal | Objectives | Interventions | Geographic focus | Timeframe |
|---|---|---|---|---|---|---|---|
| | | | | | adult HIV care, Tb, HTC, laboratory and health information systems | | |
| Lighthouse | Irish AID, MoH, CDC, NAC, CAFOD & London School of Tropical Medicine | The Lighthouse exists to fight against AIDS in Malawi by providing a continuum of quality care and support and by working to build capacity in the Health Sector | Lighthouse works to build capacity in HIV / AIDS care and treatment in Malawi, providing training and ongoing support, in collaboration with the Ministry of Health | To increase access of HCT, To provide quality of care and treatment of HIV related disease, To provide integrated TB HIV services, and referral for PMTCT mums and provides a comprehensive and continuous patient education programme, therapeutic feeding to malnourished patients, and follows up lost HAART patients with our Back2Care program. | HTC, HBC, ART,TB and PMTCT Integration, Community treatment and adherence | Lilongwe but clients come from all the 3 regions of Malawi | Started in 2004 and will continue to exist based on continued funding |
| BRIDGE ll | John Hopkins, Pact Malawi, Save the children, Story workshop, Galaxy, NAPHAM, YONECO, Nanzikambe & International | Not provided | Contribute towards reduction of new HIV infections *through* Promoting normative behavior change and increasing HIV preventive behavior among the adult | Strengthen individual perception of HIV risk & self-efficacy to prevent HIV infection, mobilize communities to adopt social norms, attitudes, and values that reduce vulnerability to HIV, strategically link HIV prevention interventions with other HIV and health services, support Malawian institutions to lead the national response | Mass communication, Community mobilization, referral & linkages and community based care | Nsanje, Chikhwawa, Blantyre, Mwanza, Neno, Phalombe, Zomba, Mulanje, Thyolo & Chiradzulu | 5 yr project |

| Name of org. | Partners | Mission | Goal | Objectives | Interventions | Geographic focus | Timeframe |
|---|---|---|---|---|---|---|---|
| | AIDS Alliance | | population in Malawi | to HIV prevention and harmonize high- quality HIV prevention services at scale | | | |
| CHAI | MoH, Dignitas, M2M and MSF | To engage and empower members of PLHIV as active members to be part of multi disciplinary committee in provision of HIV services | Not provided | To increase number of pregnant women in PMTCT, to link MIP to ART clinic, to decrease number of children defaulting ART, increase number of children accessing paediatric ART, increase access to EID services, strengthen the paediatric psychosocial and strengthen referral | PMTCT oriented program ( paediatric EID, ART, MIP) | Machinga | 2008- 2011 Sept |
| Dignitas | USAID, MoH, Emmanuel International & Community CBOs | Equittable access to HIV/AIDS related prevention, treatment and care is available to all regardlessof wealth, gender and geography | To increase access to effective HIV/AIDS related prevention, treatment and care in resource poor settings by developing and disseminating solutions which harness the poor of the community | To reduce new HIV infections, to improve treatment care and support for PLHIV and strengthen health systems | HIV related disease comprehensive care, ART, PMTCT & HTC,capacity building for primary health care and IExpert Client | Zomba only has Expert Clients, new districts are Machinga, Balaka, Phalombe, Mangochi & Mulanje | 2010- 2013 |
| MSF Belgium | MoH, WVI, NAPHAM, District Assembly, Support groups | Not provided | To improve access and uptake of quality HIV services | To increase uptake of services, increase drug adherence | HIV care (PMTCT, HTC,ART), OI management, mentoring and human resource | Thyolo district | 1997- 2013 |

| Name of org. | Partners | Mission | Goal | Objectives | Interventions | Geographic focus | Timeframe |
|---|---|---|---|---|---|---|---|
| | | | | | support, | | |
| M2M | MoH, CHAM, CHIDEV, MSH, EGPAF, PATH, DREAM, MSF, CHAI | **m2m** envisions a world in which all HIV+ pregnant women have babies who are <u>not</u> infected with HIV/AIDS, where HIV+ mothers live long and healthy lives, raising their children and caring for their families | To increase access to care and treatment for mothers to prolong life and reduce HIV transmission for babies | To prevent babies from contracting HIV through mother- to- child transmission, To keep HIV- positive mothers and their infants alive and healthy by increasing their access to health- sustaining medical care and to empower and enable HIV- positive mothers to live positively | Health talks, Individual education and support,Group education and support, Referrals to other organizations in the community and different delivery points of services i.e FP, Nutrition etc,Support groups and Active Client follow- up | Lilongwe, Dedza, Balaka, Mangochi, Blantyre, Chikhwawa and Nsanje | 2008-indefinate |
| MSH | Ministry of Health, Light house, Baylor & UNC | Not provided | Not provided | Not provided | C IMCI, Nutrition support to malnourished children, HIV services to everyone, Community HIV testing & MIP | Phalombe, Chikhwawa, Salima and Zomba | 2007- 2011 sept |

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| Name of org. | Partners | Mission | Goal | Objectives | Interventions | Geographic focus | Timeframe |
|---|---|---|---|---|---|---|---|
| PSI/PACT MALAWI | Macro, Society of women and AIDS in Malawi, MoH, Christian community church, Southern AID Trust and NASO | Not provided | To promote behaviour change for reducing HIV infection in Malawi | To increase access of HIV services through referrals working with DHOs, to promote condom use, to enhance behaviour change among specific cadre of people like fishermen, sex workers and plantation workers and to carry out research for evidence based programming | Support partners to promote access of HIV services, Interpersonal communication, Dissemination of messages through various channels and production & distribution of IEC materials | Mulanje, Nkhotakota, Mangochi, Mchinji, Nkhatabay, Mzuzu, Mwanza, Thyolo and Lilongwe | 2009- 2014 |